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The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research

By Anne Corden, Roy Sainsbury, Annie Irvine and Sue Clarke

Aims and objectives

The aims of the qualitative research reported here were to investigate the use and impact of Disability Living Allowance (DLA) and Attendance Allowance (AA), to increase understanding of the difference these benefits made to people's lives, and to contribute towards development of questions that might be used in further surveys.

Research methods

The study used the following methods:

- Six group discussions with 24 professionals and advisers in touch with people who claim or might be entitled to DLA or AA.
- Qualitative interviews with 15 adult DLA recipients, 15 AA recipients and 15 parents of child recipients of DLA.
- A desk-based review of relevant survey instruments.

Group discussions were held in early 2009. The 24 people who took part in the discussion groups included Department for Work and Pensions (DWP) staff in the Benefits Enquiry Line, and Carer's Allowance office; staff in six local offices of PCDS; local authority staff from adult services in seven local authorities; staff working in advice agencies and people working in voluntary organisations.

The study group of adult DLA and AA recipients and parents of children receiving DLA was purposively selected from a sample supplied by DWP of benefit recipients who lived in one of three locations (a city, an urban and a rural environment) in Great Britain. Fieldwork was conducted during the summer of 2009. The

overall group included a range of people with different ages and personal circumstances, and a roughly equal gender balance. One-third of the adult DLA recipients were aged over 65 years. Interviews were recorded, and transcriptions used for thematic qualitative analysis.

Key findings

Information and advice about DLA and AA

There was a wide range of circumstances in which DWP staff and personnel in other statutory and voluntary services talk to people about DLA and AA. Advisers' experience was that general levels of knowledge about these benefits were low, and they spend considerable time correcting misunderstandings and wrongly based concerns. Advisers frequently discussed with potential applicants and their families what DLA or AA was for and how it might be used.

The consensus among advisers was that, generally, DLA and AA had a major positive impact on recipients' lives. From their experience, they believed that DLA and AA benefited people by helping them:

- maintain independence and control;
- meet some of the extra costs of disability;
- improve quality of life;
- keep jobs or maintain contact with the labour market;
- access other help and services (through 'passporting');
- enhance physical and mental health;

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- maintain warmer, cleaner, more comfortable homes;
- relieve financial pressures.

Recipients' conceptualisation of DLA and AA

Adult recipients of DLA and AA perceived entitlement to be related to effects of long-term medical conditions and the need for help or care, or as a general boost to income for people with problems related to their condition. Parents also related entitlement to their child's medical condition and the additional expenses involved, and some saw wider purpose in enhancing family life, taking pressures off parents, and replacing lost earnings.

Using DLA and AA

Findings showed an important difference between the practical money management of DLA and AA received, and the way in which recipients explained how the benefits enabled spending. The former was to do with the way bank accounts and post office accounts were used, how people made direct debits and standing orders to pay some bills, and which partner took responsibility for different parts of household budgeting.

In addition, while some people separated out their DLA or AA (and sometimes other particular income streams) for particular purposes, others preferred a 'general pot' approach, thinking about the total money available to them, and paying for things as they were needed. Payment intervals for different pensions and benefits, including DLA or AA, the relative amounts received, and people's approaches to saving were all influential.

When we turn from practical money management to thinking about how DLA or AA was being used to enable spending, findings show that DLA and AA paid to adult recipients enabled them to meet expenses of:

- personal care;
- transport;
- food;
- fuel;
- home maintenance, including cleaning, gardening and small jobs;
- health care, medical equipment and supplies;
- telephones and computers;
- social activities;
- giving presents, gifts and 'treating'.

Findings showed that most direct personal care and support of elderly and disabled people living in the community was unpaid, and provided by partners, adult children and other family members. For many DLA and AA recipients, managing daily living also depended on finding solutions and working out ways of doing things which reduced the amount of direct help they needed, and enabled them to maintain control and some independence. Life was managed by being able to afford market prices for housework, laundry, garden maintenance, odd jobs and taxi rides; by buying frozen meals or buying hot meals outside the home; by relying on frequent use of telephones, and by running private vehicles. DLA and AA helped people to be able to afford these things.

All parents of child recipients of DLA wanted opportunities to give their child the best possible life chances. They spent money on the particular equipment or activities that would help, and on treatment and tuition. Some parents had heavy expenditure on heating, electricity, transport and costs of maintaining or replacing appropriate clothes and shoes. Expenses spread across other family members, and into all areas of family life. Having DLA helped them pay for such items and services.

Other roles for DLA and AA

In addition to the way in which DLA and AA enabled people to afford what they needed, people attributed other roles to the benefits:

- Helping practical money management.
- Enabling access to other kinds of support (through 'passporting').
- Providing a safety net, especially during financial transitions.
- Preventing, or helping management of, debts.
- Enabling people to live at home.
- Keeping people part of society.
- Acknowledging people's condition.
- Enabling paid work.

What difference did recipients think was made by DLA or AA?

DLA recipients of working age were unanimous in expressing views that DLA made a big difference to them. All the adult DLA recipients in our study group were people who had been living on low out-of-work incomes for some time. Typical comments were that DLA 'enables me to live'. Some said, without DLA, they would not be able to pay their bills, or get the help they needed.

Parents of child recipients who were living on low incomes said their children's lives would be adversely affected, for example, spending less on items needed for their disabled child, such as extra lessons. However, the more generally reported effect would be reduction in living standards for the whole family.

Among DLA recipients over state retirement age and AA recipients who engaged with the idea of what difference the benefit made most also used strong language. Some said it made the difference between poverty and a reasonable standard of living and without AA they could not afford the help they had, could not afford chiropody, or keep their home clean and warm.

Conclusions

Findings showed a wide range of ways in which DLA and AA are currently enabling elderly and

disabled people to afford to pay for services and items they need. The benefits have preventive roles in helping people avoid moves into residential care or nursing homes, and maintaining or avoiding deterioration in health. Importantly, while DLA or AA often does not go directly towards paying for personal care, the benefits have a key role in reducing potential demand for formal services. This happens by enabling people to find their own solutions, both in the market place, and in accessing services from voluntary organisations, which are often not cost-free for users. DLA and AA recipients also believed that the gifts and 'treats' they were able to give to relatives and friends who gave practical care and help helped to maintain the channels of informal support within families and communities, on which they depended.

For child recipients of DLA, parents were using the benefit in ways that will enhance their child's future life chance and opportunities. They were paying for tuition, physiotherapy, speech and language therapy, and equipment to encourage learning and stimulate response, all with a view to the future development of the child. In some families, DLA was being used in ways which support and strengthen family life.

Methodological findings

Our qualitative approach in interviews with DLA and AA recipients was to seek contextual information about effects of health circumstances and managing daily life, sources of income, money management, expenses and spending decisions. Embedded throughout this discussion were different opportunities to consider the contribution made by DLA or AA.

We were able to explore the difference made by DLA or AA in a number of ways, (through spontaneous comments; direct questions; prompts; exploration of advice received; exploration of perceived reasons for receipt; exploration of perceived relationship between DLA, AA and paid work; exploration of feelings about receipt; exploration of practical money

management and response to hypothetical scenarios of loss and gain in income).

Useful information came from each of these different ways of investigation, but the overall picture of how DLA and AA were being used and what difference they made depended on our having used all the approaches.

Conclusions from methodological findings

One of the principal aims of the research was to inform the possible development of quantitative research instruments for measuring the difference made by DLA and AA. The main relevant findings were:

- Measuring impacts of DLA and AA does not require asking questions about the use of the benefits.
- Process questions would provide a fuller understanding of the role of DLA and AA in people's lives.
- There are significant differences between the needs and experiences of adult benefit recipients (of DLA and AA) and parents of child recipients of DLA.

The two main options are, therefore, to design a survey based on inputs and impacts only, or to design a survey that includes questions about how DLA and AA are perceived and used. The first option would not require constructing questions about DLA and AA while the latter option would definitely require a suite of questions that does not currently exist.

It was outside the scope of this study to make any assessment or recommendations about whether any existing survey could in some way contribute to, or be used as the basis for, a survey of DLA and AA recipients.

However, scrutiny of relevant surveys suggests that none appears sufficient to measure the impacts of the benefits. A comprehensive understanding of the impacts of DLA and AA would, therefore, require a large dedicated survey instrument.

The full report of these research findings is published by the Department for Work and Pensions (ISBN 978 1 84712 756 3. Research Report 649. July 2010).

You can download the full report free from: <http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

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